

# Incorporating social justice and stigma in cost-effectiveness analysis: drug-resistant tuberculosis treatment

A. Zwerling,<sup>\*†</sup> D. Dowdy,<sup>\*</sup> A. von Delft,<sup>\*§</sup> H. Taylor,<sup>\*¶</sup> M. W. Merritt<sup>\*¶</sup>

<sup>\*</sup>Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA; <sup>†</sup>School of Epidemiology & Public Health, University of Ottawa, Ottawa, Ontario, Canada; <sup>‡</sup>TB Proof, Cape Town, South Africa; <sup>§</sup>School of Public Health and Family Medicine, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa; <sup>¶</sup>Johns Hopkins Berman Institute of Bioethics, Baltimore, Maryland, USA

## SUMMARY

Novel therapies for multidrug-resistant tuberculosis (MDR-TB) are likely to be expensive. The cost of novel drugs (e.g., bedaquiline, delamanid) may be so prohibitively high that a traditional cost-effectiveness analysis (CEA) would rate regimens containing these drugs as not cost-effective. Traditional CEA may not appropriately account for considerations of social justice, and may put the most disadvantaged populations at greater risk. Using the example of novel drug regimens for MDR-TB, we propose a novel methodology, ‘justice-enhanced CEA’, and demonstrate how such an approach can simultaneously assess social justice impacts alongside traditional cost-effectiveness ratios. Justice-enhanced CEA, as we envision it, is performed in three steps: 1) systematic data collection about patients’ lived experiences, 2) use of empirical findings to inform social justice assessments, and 3) incorporation of data-informed social justice assessments into a decision analytic

framework that includes traditional CEA. These components are organized around a core framework of social justice developed by Bailey et al. to compare impacts on disadvantage not otherwise captured by CEA. Formal social justice assessments can produce three composite levels: ‘expected not to worsen...’, ‘may worsen...’, and ‘expected to worsen clustering of disadvantage’. Levels of social justice impact would be assessed for each major type of outcome under each policy scenario compared. Social justice assessments are then overlaid side-by-side with cost-effectiveness assessments corresponding to each branch pathway on the decision tree. In conclusion, we present a ‘justice-enhanced’ framework that enables the incorporation of social justice concerns into traditional CEA for the evaluation of new regimens for MDR-TB.

**KEY WORDS:** stigma; human rights; economic evaluation; ethics; MDR-TB

ECONOMIC EVALUATION commonly takes the form of cost-effectiveness analysis (CEA), and compares the costs and health effects of interventions to help direct limited health care resources toward those activities that provide the greatest ‘value for money’.<sup>1</sup> CEAs generally report incremental cost-effectiveness ratios, expressed as incremental cost per incremental health outcome. For example, relative to the existing standard of care for a given condition, a novel intervention might cost US\$1000 (incremental cost) per additional year of life gained (incremental health outcome). Such assessments help decision-makers to determine which interventions will maximize beneficial health outcomes per dollar spent.

Unfortunately, CEA may lead to policy recommendations that harm disadvantaged groups as an unintended consequence.<sup>2,3</sup> Take the example of novel drugs for multidrug-resistant tuberculosis (MDR-TB): bedaquiline<sup>4</sup> and delamanid.<sup>5</sup> These drugs are more expensive than those in current use;

it may be less costly (and equally effective) to maintain standard MDR-TB regimens vs. implementing novel MDR-TB regimens. Standard regimens, which typically require more hospitalizations and/or longer treatment durations than novel regimens, may expose patients to significantly higher risks of treatment-induced disadvantages such as stigma. Finding ways to assess impacts on social disadvantage such as stigma alongside the traditional CEA is critical to enabling clinicians, policy makers, academic allies, and funders to develop MDR-TB treatment policies that are more fair and thereby more responsive to the needs of the populations they serve.

Social justice is an ethical consideration prominent in the school of political philosophy inspired by Rawls’s work on justice<sup>6,7</sup> and Sen’s work on inequality,<sup>8,9</sup> and carried forward by theorists such as Daniels, Nussbaum, and Powers and Faden.<sup>2,10,11</sup> It calls for fairness and equity in the distribution of

societal advantages and disadvantages, including the impacts of health policy choices, and a commitment to social justice is central to public health.<sup>12,13</sup> Stigma has been defined as ‘a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation, that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group’.<sup>14</sup> TB has long been a highly stigmatized disease, and accounting for stigma within social justice assessments of TB interventions should be considered a key element in moving CEAs forward.

Policy choices involving social justice may present trade-offs between maximizing net benefit and combating severe disadvantage.<sup>2,12,15,16</sup> To conduct fully informed policy deliberations, decision makers should be able to represent such trade-offs explicitly, but traditional CEA does not equip them to do so.<sup>2</sup> We used the example of MDR-TB treatment to introduce the concept of a new methodology that we term ‘justice-enhanced CEA’ (JE-CEA). We show how JE-CEA can assess impacts on social justice alongside traditional cost-effectiveness ratios, and we suggest how it may support better-informed policy decisions (Table).

### MULTIDRUG-RESISTANT TUBERCULOSIS: STANDARD VS. NOVEL TREATMENT REGIMENS

TB disproportionately affects populations that are already disadvantaged.<sup>17</sup> It may also exacerbate pre-existing disadvantage not only through the physical, social, and financial hardships of the disease itself, but also through lengthy, burdensome treatment that may exacerbate the disadvantages of stigma, shame, social isolation, loss of agency and family strain.<sup>18,19</sup> With lower cure rates and higher fatality rates, MDR-TB carries even greater stigma and fear than drug-susceptible TB, as well as longer, more burdensome treatment.<sup>20,21</sup>

Novel MDR-TB treatment regimens are still under investigation, but early studies suggest the possibility of similar or higher cure rates with fewer side effects.<sup>5,22,23</sup> Bedaquiline (BDQ) and delamanid (DLM) have both shown early evidence of efficacy, both are taken orally, potentially eliminating the current need for painful daily intramuscular injections at health care facilities.<sup>24</sup> These novel agents come at exceptionally high prices: for example, current prices for DLM in Europe exceed US\$28 000 for a 6-month course, or US\$150 daily.<sup>25</sup> Because of this price differential, traditional CEA might not deem regimens using these high-priced novel agents to be cost-effective, although they could transform treatment for patients from a 2-year course—including 8 months of frequently crippling daily injections in a hospital or remote facility—into a 9-month, fully oral regimen.<sup>26,27</sup> From the standpoint

of the commitment to social justice that is central to public health,<sup>13,28</sup> the inability to compare explicitly the impact of different policies on the distribution of disadvantage alongside incremental cost-effectiveness using CEAs is ethically suboptimal.

### THE SOCIAL JUSTICE FRAMEWORK

A formal methodology to account for impacts on disadvantage in the context of CEA can be constructed using the core framework of social justice recently synthesized by Bailey et al.<sup>19</sup> This approach proceeded by locating areas of agreement among a family of theories of social justice that deploy ‘multidimensional metrics of human well-being’, where each theory identifies certain dimensions of well-being that people generally have reason to value as ‘basic determinants of the character and quality of human life’.<sup>2,9–11,15,28–32</sup> Bailey et al. sought to identify the points of ‘convergence or overlap’ so that the resulting framework would be a basis for ethical analysis in the context of public health policymaking.<sup>19</sup>

Three core dimensions of human well-being were identified: 1) agency—the ability to lead one’s life and engage in activities one finds meaningful; 2) respect—the recognition of one’s equal moral value, worth, and dignity as a person; and 3) association—the ability to engage in a full range of intimate, familial, friendly, community, economic, and civic relationships with others.<sup>28</sup> As a fourth point of convergence to complete the core framework, Bailey et al. identified ‘a shared principle of prioritization’ as follows:<sup>19</sup>

...it is a priority and duty of justice to avert and alleviate clusters of disadvantage in multiple dimensions of well-being. As Powers and Faden argue, justice requires that priority be given to addressing systematic disadvantages that cut across multiple core dimensions of well-being.<sup>3</sup> Wolff and deShalit argue for a duty to prioritize social institutions, programs, and policies that ‘decluster disadvantage,’ breaking up vicious cycles through which disadvantages in some dimensions of well-being coexist with and reinforce disadvantages in other dimensions.<sup>8</sup> Venkatapuram has also endorsed this norm.<sup>29</sup>

Within the context of TB, stigma can impact on each of these three dimensions of well-being. For example, TB stigma may impact agency or the ability to lead one’s life and engage in activities one finds meaningful through enacted or experienced stigma (also known as discrimination), and structural stigma such as policies or laws may also impact one’s agency.<sup>33,34</sup> Anticipated or perceived stigma may result from the belief in some communities that one is devalued or ‘less than’ others once they have been diagnosed with TB; this type of stigma impacts on the

**Table** Current limitations in traditional CEA and examples of ways JE-CEA may bolster traditional CEA

Current gaps in traditional CEA	Advantages of a JE-CEA approach
No formal assessment of social justice May promote policy choices that are cost-effective but contribute to further clustering of disadvantage Cannot provide information to highlight areas of negative social impacts for standard or novel interventions Does not systematically include certain major considerations of social justice relevant to decisions that economic evaluation is used to inform	Introduces the language of social justice into CEA Encourages the inclusion of formal assessments of social justice impacts in future decision and policy making Provide key information surrounding social justice necessary for advocacy (e.g., price negotiations of novel drugs for resource-limited settings) Highlights the need for data collection activities to inform future formal social justice assessments Presents considerations of social justice simultaneously with those of cost-effectiveness

CEA = cost-effectiveness analysis; JE-CEA = justice-enhanced CEA.

respect dimension and can lead to delayed diagnosis and poor treatment adherence.<sup>35</sup> Secondary or courtesy stigma is present if family, friends and colleagues may expect a negative attitude because of their link with TB. This can lead to important impacts on patients' dimension of association and can limit their regular activities and support opportunities.<sup>36</sup>

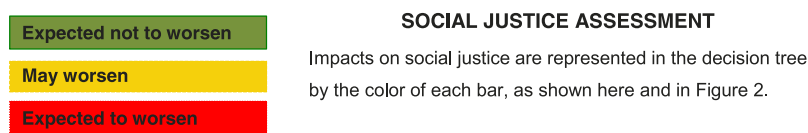
Specific policy choices can be compared in terms of their expected impact on the clustering of disadvantage across core dimensions of well-being.<sup>15</sup> A just decision process for questions of health policy ought at least to avoid exacerbating the clustering of disadvantages in affected populations.<sup>2</sup> The failure to anticipate and avert such policy outcomes would undermine social justice by worsening the plight of people in society who were already relatively badly off before enactment of the policy, and who may have come into the line of fire of adverse policy impacts through the very pre-existing circumstances by which they were already disadvantaged. For example, TB stigma may be worsened by an increased number or duration of visits to health care facilities or prolonged hospitalization. Novel treatment regimens may reduce the number of visits and/or duration, leading to a reduction in experienced or anticipated stigma. These impacts should be accounted for in CEA, otherwise these important social justice impacts may be overlooked.

## JUSTICE-ENHANCED COST-EFFECTIVENESS ANALYSIS

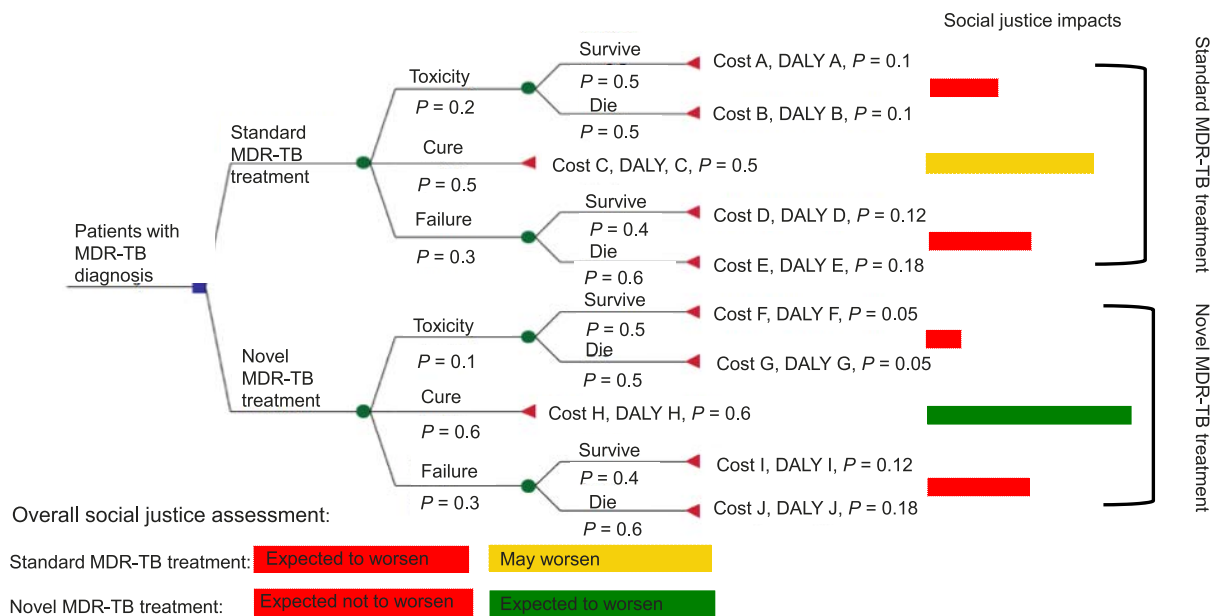
We propose a systematic, data-informed methodology called JE-CEA. For any given policy question to which CEA is applicable, JE-CEA is a social justice

assessment that enables decision makers to explicitly consider expected impacts on the clustering of disadvantages. Using three impact levels, the social justice assessment for a given scenario under analysis could be either 'expected not to worsen...', 'may worsen...', or 'expected to worsen...', as color-coded in Figure 1. We use the language of 'worsening' here because, as noted above, a just decision process for questions of health policy ought at least to avoid exacerbating the clustering of disadvantages in affected populations.<sup>2</sup> In the context of scaling up novel MDR-TB regimens, our assumption is that successful treatment of the disease constitutes the main vehicle for alleviating disease-imposed disadvantage. JE-CEA is designed to support the comparison of approaches in terms of their unintended and unwelcome propensities to exacerbate clustering of disadvantages across core dimensions of well-being—agency, association, and respect.

These assessments are compiled using empirical findings tracking the occurrence, magnitude, and breadth of cross-cutting impacts on the three core dimensions of well-being. For example, empirical findings may indicate that even patients who experience cure on MDR-TB treatment may suffer marital strife or public ridicule as a result of prolonged hospitalization. An MDR-TB cure requiring hospitalization might accordingly be associated with adverse impacts of moderate magnitude across a breadth of two core dimensions of well-being: association (social isolation) and respect (stigma). Such levels of social justice impact could be assessed for each major type of outcome under the treatment regimens to be compared. As a simplified example, we show hypothetical assessments in Figure 2 with



**Figure 1** Impact on social justice to be overlaid over a traditional CEA decision tree. This image can be viewed online in colour at <http://www.ingentaconnect.com/content/iatld/jtld/2017/00000021/a00111s1/art00011>



**Figure 2** Hypothetical, simplified example of a proposed methodology incorporating social justice. In this simplified decision tree, we present a representation of how social justice assessments may be overlaid with the decision analysis framework corresponding to particular ‘branches’ in the model. The colors of the bars represent the expected impact on social justice experienced on average across each branch pathway, whereas the length of the bars correspond to the proportion of the cohort experiencing that particular social justice impact. For the overall social justice assessment, assessments are concatenated across each intervention arm. DALY = disability-adjusted life-years; MDR-TB = multidrug-resistant tuberculosis; ICER = incremental cost-effectiveness ratio. This image can be viewed online in colour at <http://www.ingentaconnect.com/content/ijatld/ijtld/2017/00000021/a00111s1/art00011>

possible outcomes of cure, toxicity, and failure. Each outcome could have a probability and an expected impact on social justice informed by empirical data for both standard and novel MDR-TB regimens.

Social justice assessments can be presented in parallel to a ‘decision tree’ as is commonly used for CEA (Figure 2). Each social justice assessment will have two dimensions: 1) the proportion of patient population exposed to each outcome (length of the bar shown in Figure 2), and 2) the level of impact on clustering of disadvantage under that outcome (color of the bar shown in Figure 2). An overall social justice assessment can be compiled by presenting summary bars for each alternative. In the hypothetical example of Figure 2, the summary bars indicate that, relative to the standard regimen, the novel regimen is favored on both dimensions of the social justice assessment (proportion exposed and level of impact).

## DATA TO INFORM JE-CEA: LIVED EXPERIENCES OF MDR-TB PATIENTS

To perform JE-CEA comparing MDR-TB treatment regimens in a given setting, empirical estimates of impact on core dimensions of well-being will be required. A qualitative evaluation is needed to determine whether, in which ways and to what extent, each regimen might worsen the clustering of disadvantage experienced by patients. For example, a meta-analysis of previous qualitative research on TB patients’ experience indicates that patient-centered

barriers to TB treatment adherence include lack of community, family, or household support.<sup>28</sup> Techniques such as in-depth interviews with MDR-TB patients and their health care providers can be used to explore social isolation as well as other ways in which MDR-TB treatment may compromise agency, respect, and association for patients. Interview findings can be used to compile formal social justice assessments, which are then incorporated into the JE-CEA decision analysis. Future work could build on qualitative findings to further refine decision analysis by developing tools to better quantify factors most likely to exacerbate disadvantage.

## SYNTHESIS

Decision makers should be empowered to assess both value for money and impact on disadvantage simultaneously, making explicit any trade-offs between them. If they are concordant, the case for making a certain decision is bolstered; if they are discordant, decision-makers should evaluate the discrepancy. In cases like the example discussed above in which the hospitalization required by standard MDR-TB treatment is associated with experiences of stigma and social isolation which could be averted by a novel (but high-cost) regimen requiring no hospitalization, the CEA component of JE-CEA (i.e., the incremental cost-effectiveness ratio), might favor the standard regimen, whereas the justice-enhanced component (i.e., social justice as-



assessment) favors the novel regimen. JE-CEA would present decision makers not only with this discrepancy, but also with the extent of relevant impacts on each side. In this type of case, JE-CEA might serve to provide the additional justification needed for policy makers to implement costly regimens to improve the plight of MDR-TB patients, and ultimately for civil society to press for reductions in the price of novel MDR-TB regimens.

## STRENGTHS AND LIMITATIONS OF THE JE-CEA APPROACH

If successfully implemented and replicated, JE-CEA could fill important gaps in the current approach to economic evaluation (Table). These include: introducing the language of social justice into economic evaluation; encouraging the awareness and inclusion of social justice impacts when making health-related decisions; highlighting the need for the collection and analysis of empirical data to demonstrate how treatment regimens can exacerbate disadvantage; and encouraging decision makers to incorporate formal assessments of social justice in key policy and resource allocation decisions. To achieve these gains, additional resources and expertise would be required to compile formal social justice assessments across different settings. It remains unclear how far such assessments may be generalizable (although the same could be said about the economic considerations of CEA). It is important to note that social justice may not be the only element lacking in CEA, and evaluations should perhaps also include assessments of fairness, equity or age preference, to name a few. The methodology proposed here is but a first step toward including elements such as social justice in a formal assessment of CEA. While transmission is a critical issue for MDR-TB control, JE-CEA at this stage relies on a decision analysis model and does not explicitly account for transmission. Future expansion of the methodology should involve transmission models.

JE-CEA methodology is currently under conceptual development. Its full elucidation remains to be borne out through empirical research and discussions with clinicians and policy makers. Further work is intended to refine this concept by including empirical estimates/observations of perceptions of social justice impacts, as well as quantitative efforts to appropriately balance cost-effectiveness and social justice considerations. Moreover, while the core framework of social justice employed in JE-CEA is derived from theories in political philosophy, it will also be important to consider social science-based frameworks for addressing issues of social justice and health, such as destigmatization.<sup>37,38</sup> Adoption of JE-CEA will require the engagement and education of key stakeholders as well as thoughtful dissemination

across various settings. Being able to see social justice assessments alongside traditional CEA outputs still leaves policy makers with difficult decisions, particularly in cases of discordance. Like traditional CEA, however, JE-CEA is designed not to replace the decision-making process but to provide a more complete picture that decision makers can use to organize and inform their deliberations. Importantly, we do not suggest that JE-CEA is the only way to incorporate social justice assessments into economic evaluation; rather, the development of JE-CEA may stimulate improved approaches that could further promote the inclusion of formal social justice assessments into traditional CEA, policy development and key decision-making processes.

## CONCLUSION

Current prevailing methods for economic evaluation do not fully address considerations of social justice. As a result, assessments of interventions, such as novel regimens for MDR-TB, may overlook important potential benefits in reducing clusters of disadvantage, thereby missing opportunities to alleviate patient burden. Although the principles of international human rights law call for a focus on vulnerable and marginalized groups,<sup>39</sup> traditional CEA does not address this need and may overlook this important principle. Here, we propose JE-CEA as an alternative approach. Formal assessments of social justice can and should be undertaken in conjunction with CEA to provide more complete information to decision makers. Otherwise, initially costly interventions (including novel regimens for MDR-TB) may never be scaled up, with the result that clinicians do not have access to certain (more expensive) treatments, clustering of disadvantage is worsened among already badly off populations, and sufficient pressure is never applied for the economics of those interventions to change. Incorporating social justice assessments into CEA can lead to more ethically responsible decision making, ultimately creating a healthier and more just society.

## Acknowledgements

Financial support for this study was provided entirely by a grant awarded to MWM by the US National Institutes of Health, Bethesda, MD, USA (1R56AI114458-01). The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report. The authors are grateful to two anonymous journal reviewers for valuable comments that enabled us to improve the manuscript.

Conflicts of interest: none declared.

## References

- 1 Drummond M, Sculpher M, Torrance G, O'Brien B, Stoddart G. *Methods for the economic evaluation of health care programmes*. 3<sup>rd</sup> ed. New York, NY, USA: Oxford University Press, 2005.

- 2 Powers M, Faden R. Social justice: the moral foundations of public health and health policy. Oxford, UK: Oxford University Press, 2006.
- 3 Brock D W, Daniels N, Neumann P J, Siegel J E. Ethical and distributive considerations. In: Neumann P J, Sanders G D, Russell L B, Siegel J E, Ganiats T G, eds. Cost-effectiveness in health and medicine. New York, NY, USA: Oxford University Press, 2017.
- 4 World Health Organization. The use of bedaquiline in the treatment of multidrug-resistant tuberculosis: interim policy guidance. WHO/HTM/TB/2013.6. Geneva, Switzerland: WHO, 2013.
- 5 Lessells R J. Delamanid for multidrug-resistant pulmonary tuberculosis. *Thorax* 2013; 68: 730.
- 6 Rawls J. A theory of justice. Cambridge, MA, USA: Harvard University Press, 1971.
- 7 Rawls J, Kelly E. Justice as fairness: a restatement. Cambridge, MA, USA: Harvard University Press, 2001.
- 8 Sen A. Inequality reexamined. Cambridge, MA, USA: Harvard University Press, 1995.
- 9 Sen A. Development as freedom. Oxford, UK: Oxford University Press, 1999.
- 10 Daniels N. Just health: meeting health needs fairly. Cambridge, UK: Cambridge University Press, 2008.
- 11 Nussbaum M C. Creating capabilities: the human development approach. Cambridge, MA, USA: Belknap Press, 2011.
- 12 Beauchamp T L, Childress J F. Principles of biomedical ethics. 7<sup>th</sup> ed. Oxford, UK: Oxford University Press, 2013.
- 13 Faden R, Shebaya S. Public health ethics. In: Zalta E N, ed. The Stanford Encyclopedia of Philosophy. Stanford, CA, USA: Stanford University Press, 2010.
- 14 Weiss M G, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. *Psychol Health Med* 2006; 11: 277–287.
- 15 Wolff J, DeShalit A. Disadvantage. Oxford, UK: Oxford University Press, 2007.
- 16 Brock D W. Ethical issues in the use of cost effectiveness analysis for the prioritization of health care resources. In: Anand S, Peter F, Sen A, eds. Public health, ethics and equity. Oxford, UK: Oxford University Press, 2004.
- 17 Grange J, Story A, Zumla A. Tuberculosis in disadvantaged groups. *Curr Opin Pulm Med* 2001; 7: 160–164.
- 18 Hargreaves J R, Boccia D, Evans C A, Adato M, Petticrew M, Porter J D. The social determinants of tuberculosis: from evidence to action. *Am J Public Health* 2011; 101: 654–662.
- 19 Lönnroth K, Jaramillo E, Williams B G, Dye C, Ravigliione M. Drivers of tuberculosis epidemics: the role of risk factors and social determinants. *Soc Sci Med* 2009; 68: 2240–2246.
- 20 Shin S S, Pasechnikov A D, Gelmanova I Y, et al. Adverse reactions among patients being treated for MDR-TB in Tomsk, Russia. *Int J Tuberc Lung Dis* 2007; 11: 1314–1320.
- 21 World Health Organization. Multidrug and extensively drug-resistant TB (M/XDR-TB): 2010 global report on surveillance and response. WHO/HTM/TB/2010.3. Geneva, Switzerland: WHO, 2010.
- 22 Diacon A H, Dawson R, von Groote-Bidlingmaier F, et al. 14-day bactericidal activity of PA-824, bedaquiline, pyrazinamide, and moxifloxacin combinations: a randomised trial. *Lancet* 2012; 380: 986–993.
- 23 Diacon A H, Pym A, Grobusch M, et al. The diarylquinoline TMC207 for multidrug-resistant tuberculosis. *N Engl J Med* 2009; 360: 2397–2405.
- 24 TB Alliance. Portfolio: clinical development. New York, NY, USA <http://www.tballiance.org/portfolio/>. Accessed August 2017.
- 25 Lessem E. An activist's guide to delamanid (Deltyba). Treatment Action Group, 2014.
- 26 Aung K J, Van Deun A, Declercq E, et al. Successful '9-month Bangladesh regimen' for multidrug-resistant tuberculosis among over 500 consecutive patients. *Int J Tuberc Lung Dis* 2014; 18: 1180–1187.
- 27 Vassall A. Cost-effectiveness of introducing bedaquiline in MDR-TB regimens: an exploratory analysis. World Health Organisation, 2013.
- 28 Bailey T C, Merritt M W, Tediosi F. Investing in justice: ethics, evidence and the eradication investment cases for lymphatic filariasis and onchocerciasis. *Am J Public Health* 2015; 105: 629–636.
- 29 Venkatapuram S. Health justice: an argument from the capabilities approach. Cambridge, UK: Polity Press, 2011.
- 30 Alkire S. Valuing freedoms: Sen's capability approach and poverty reduction. Oxford, UK: Oxford University Press, 2002.
- 31 Crocker D A. Ethics of global development: agency, capability, and deliberative democracy. Cambridge, UK: Cambridge University Press, 2008.
- 32 Ruger J P. Health and social justice. Oxford, UK: Oxford University Press, 2010.
- 33 Coreil J, Mayard G, Simpson K M, Lauzardo M, Zhu Y, Weiss M. Structural forces and the production of TB-related stigma among Haitians in two contexts. *Soc Sci Med* 2010; 71: 1409–1417.
- 34 Baral S C, Karki D K, Newell J N. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health* 2007; 7: 211.
- 35 Somma D, Thomas B E, Karim F, et al. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *Int J Tuberc Lung Dis* 2008; 12: 856–866.
- 36 Craig G M, Daftary A, Engel N, O'Driscoll S, Ioannaki A. Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. *Int J Infect Dis* 2017; 56: 90–100.
- 37 Berezin M, Lamont M. Mutuality, mobilization, and messaging for health promotion: toward collective cultural change. *Soc Sci Med* 2016; 165: 201–205.
- 38 Clair M, Daniel C, Lamont M. Destigmatization and health: cultural constructions and the long-term reduction of stigma. *Soc Sci Med* 2016; 165: 223–232.
- 39 United Nations Committee on Economic, Social and Cultural Rights. The nature of States Parties' obligation. New York, NY, USA: UN CESCR, 1990.

## R É S U M É

Les nouveaux traitements de la tuberculose multirésistante (TB-MDR) seront probablement coûteux. Le coût des nouveaux médicaments (par exemple la bédaquiline, le délamanide) pourrait être si élevé qu'une analyse de coût-efficacité traditionnelle (CEA) classerait les protocoles contenant ces médicaments comme non rentables. Une CEA traditionnelle pourrait ne pas tenir suffisamment compte des considérations de justice sociale et pourrait faire courir davantage de risque aux populations les plus défavorisées. En utilisant l'exemple des protocoles de médicaments nouveaux pour la TB-MDR, nous démontrons une nouvelle méthode, « CEA plus équitable/orienté vers la justice sociale », et montrons qu'une telle approche peut simultanément évaluer les impacts en matière de justice sociale parallèlement aux ratios traditionnels de coût efficacité. La CEA plus équitable, telle que nous la voyons, est réalisée en trois étapes : 1) un recueil systématique de données relatives aux expériences vécues par les patients ; 2) le recours à des constatations empiriques afin d'éclairer les

évaluations de justice sociale ; et 3) l'incorporation d'évaluations de justice sociale basées sur des données dans un cadre de décision analytique qui inclut la CEA traditionnelle. Ces composants sont organisés autour d'un cadre central de justice sociale élaboré par Bailey et al. afin de comparer les impacts sur les personnes défavorisées qui ne sont pas autrement capturés par la CEA. Les évaluations formelles de justice sociale peuvent produire trois niveaux composites : « ne devrait pas aggraver ... », « pourrait aggraver... » et « pourrait aggraver le regroupement des patients défavorisés ». Les niveaux d'impact sur la justice sociale seraient évalués pour chaque type principal de résultats dans chaque scénario politique. Les évaluations de justice sociale sont alors utilisées en parallèle avec des évaluations de coût efficacité correspondant à chaque branche de l'arbre de décision. En conclusion, nous présentons un cadre plus soucieux de justice qui permet l'incorporation de préoccupations de justice sociale au sein de l'analyse traditionnelle coût efficacité pour l'évaluation de nouveaux protocoles de TB-MDR.

## R E S U M E N

Es muy probable que los nuevos tratamientos contra la tuberculosis multirresistente (TB-MDR) sean costosos. Los costos de los nuevos fármacos (por ejemplo, la bedaquilina y el delamanid) pueden ser tan excesivamente altos que los análisis habituales de costoefectividad (CEA) calificarían los regímenes que los contienen como ineficaces con relación a los costos. Los análisis corrientes tal vez no tienen en cuenta de manera adecuada los aspectos de justicia social y pueden hacer correr mayores riesgos a las poblaciones más desfavorecidas. Al analizar el ejemplo de los nuevos regímenes de medicamentos contra la TB-MDR, se demuestra un nuevo método, CEA orientado por la justicia, y se pone en evidencia que este enfoque evaluó de manera simultánea las repercusiones en materia de justicia social y los cocientes tradicionales de costoefectividad. Los CEA orientados por la justicia, como se proponen aquí, se llevan a cabo en tres etapas, a saber: 1) la recogida sistemática de datos sobre las experiencias vividas por los pacientes; 2) la utilización de los resultados empíricos con el fin de fundamentar las evaluaciones de justicia social; y 3) la incorporación de

las evaluaciones de justicia social fundamentadas en los datos, en un marco decisional analítico que incluye los CEA tradicionales. Estos componentes se estructuran alrededor de un marco básico de justicia social elaborado por Bailey y colegas, a fin de comparar las repercusiones en las poblaciones desfavorecidas, que no se captan en los estudios tradicionales. Las evaluaciones formales de justicia social dan lugar a tres niveles combinados: 'se prevé que no se agrave...'; 'puede agravarse...', y 'se prevé que se agrave la conglomeración de las desventajas'. Los niveles de repercusión en materia de justicia social se evaluarían en cada uno de los principales tipos de resultados y con cada marco hipotético de normas que han de compararse. Luego se disponen, una al lado de la otra, las evaluaciones de justicia social y las evaluaciones de costoefectividad que corresponden a cada rama en el árbol decisional. En resumen, en el presente artículo se presenta un marco orientado por la justicia, que favorece la incorporación de las preocupaciones de justicia social en los CEA habituales, cuando se evalúan los nuevos regímenes de tratamiento de la TB-MDR.